

# Case Management of Human Immunodeficiency Virus–Infected Injection Drug Users: A Case Study in Rio de Janeiro, Brazil

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The provision of care and support to persons living with human immunodeficiency virus (HIV) in Brazil who also use drugs and/or alcohol represents special challenges because of the combined effects of addiction, poverty, stigma, and discrimination. This paper presents details on a program providing both clinic- and field-based care to HIV-infected injection drug users, highlighting the use of a specialized case management approach to address the clinical and psychosocial needs of this population. This program includes both a mobile case management team that fosters group discussions and provides individual counseling, and provision of medical consultations at 2 major drug treatment centers in Rio de Janeiro. The article also describes the experience of working with injection drug users who regularly attend an outpatient clinic serving marginalized communities through the use of mutual self-help groups and specialized support groups to address the issue of adherence to antiretroviral therapies for the treatment of HIV/acquired immunodeficiency syndrome.

Advances in HIV treatment have resulted in substantial increases in longevity and quality of life among people living with HIV/AIDS in developed countries [1, 2]. In this respect, Brazil represents a new paradigm in being the first developing country to provide full access to combination antiretroviral therapies and therapeutic monitoring at no cost to persons who have clinical indications for their use [3]. Universal access to antiretroviral therapy was established by Brazilian federal law no. 9.313 on 13 November 1996. This law states: “HIV-infected people and/or people living with AIDS

are entitled to receive, at no cost, all medicines necessary for their treatment, from the National Health System” [4].

Since the HIV/AIDS epidemic began in Brazil, an increasing proportion of HIV/AIDS cases have been attributed to injection drug use. In the south and southeast metropolitan areas in particular, injection drug users (IDUs) and their sex partners have played a pivotal role in local HIV/AIDS dynamics [5, 6]. As in developed countries, treatment of HIV-infected drug users presents considerable challenges. Beyond dependence on opiates, stimulants, alcohol, or other drugs of abuse, this population often has other psychiatric problems, including depression, anxiety, and antisocial personality disorder [7–10]. Drug users are typically mobile, jobless, and homeless and have criminal records and difficult family relationships, making them especially vulnerable to the risk of nonadherence to antiretroviral therapy and the lack of basic access to the general health care that they often need. Yet several studies have indicated that this population can be

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treated effectively with antiretrovirals [11–13], and, because HIV-infected IDUs are frequently involved in high-risk social networks, it may be possible to reduce sexual and parenteral transmission risks to others in the community by significantly reducing their HIV load through effective antiretroviral treatment.

Some studies have addressed the difficulties experienced by HIV-infected IDUs in accessing and adhering to long-term antiretroviral therapy and the need to develop new approaches to tailor initiatives to their specific needs [11, 14–16]. For example, HIV-infected IDUs receiving methadone maintenance treatment are significantly more likely to be receiving antiretroviral therapy [16–18]. Moatti et al. [12] similarly found that HIV-infected drug users receiving buprenorphine have modestly higher adherence to antiretroviral regimens. Unfortunately, in practice, opiate agonist therapies are not available in Brazil and may be of limited value because the major drug of abuse is cocaine.

Other studies have evaluated health care professionals' attitudes and difficulties in providing care and assistance to HIV-infected IDUs [19], as well as HIV-infected IDUs' self-reported barriers in accessing and adhering to antiretroviral therapy [12, 20]. Stigma and discrimination by care providers and health care systems play a key role in decreasing access to quality care for these persons. An important gap in knowledge and interventions targeting treatment and care of HIV-infected IDUs still exists.

To date, data that could help guide interventions to improve adherence to antiretrovirals among IDUs in Brazil are lacking. As an attempt to begin to fill this gap, we present our experience with case management of HIV-infected IDUs in Rio de Janeiro. We present a case study about an ongoing initiative being implemented at Ambulatório da Providência, an outpatient unit located in downtown Rio de Janeiro. This initiative's main objective is to improve HIV-infected IDUs' quality of life by providing comprehensive medical and psychosocial support in the context of universal access to antiretroviral therapy.

## **THE ROLE OF CASE MANAGEMENT IN THE CARE OF MARGINALIZED AND DISENFRANCHISED POPULATIONS**

Case management is an integrated approach to improve access to both clinical care and psychosocial services. It has been used successfully among drug users and other underserved populations in the United States [21–23] and it also contributes to improving access to medical service use among HIV-seropositive gay men [24] and HIV-seropositive IDUs [21]. Case management is an important ancillary service for enabling access to care and optimal health service use, adherence to substance

abuse treatment, and adherence to antiretroviral therapy among current and former IDUs with HIV/AIDS [21].

Case management, specifically that focused on drug abuse, has traditionally been used to enhance access and adherence to drug treatment services [23, 25, 26] and to cater to the specific needs of HIV-seropositive drug users [27, 28]. For drug users with HIV/AIDS, case management is a tool to help patients maneuver through the health care system by helping them improve antiretroviral therapy adherence, manage drug abuse and avoidance of relapses, and access other specific services [15, 21, 29, 30]. In the program we described here, we have applied case management to improve adherence to substance abuse treatment (provided on site or through referral) and to antiretroviral therapy (on site) and to foster engagement in activities that can reduce drug-related harm.

As described by Siegal [23] in an overview of case management for substance abuse treatment, “case management generally can be described as a coordinated approach to the delivery of health, substance abuse, mental health, and social services, linking clients with appropriate services to address specific needs and achieve stated goals.” Although different models of case management exist, our program may be considered an “informal partnership model,” whereby staff members from different agencies work collaboratively, but informally, as a temporary team constituted to provide multiple services for needy clients on a case-by-case basis, sharing the responsibility for client's well-being [23].

Whereas the role of case management in the prevention of HIV transmission has not been convincingly demonstrated in the drug addict population, such strategies may help people adhere to antiretroviral therapeutic regimens, which may indirectly reduce their infectiousness [31], and at the same time assist in the recovery from chaotic and self-destructive behaviors.

## **THE RIO DE JANEIRO EXPERIENCE**

In the Brazilian context, case management of people living with HIV/AIDS who are IDUs has seldom been attempted. Successful programs, such as that described below for Rio de Janeiro, as well as some initiatives aiming to integrate primary care units and syringe exchange programs, have been implemented in southern Brazil [32], but these are exceptions rather than the rule.

To the best of our knowledge, the first attempt to use case management targeting IDUs in Brazil was accomplished by the research team of the World Health Organization phase II study, coordinated by one of the present authors (F.I.B.), through a consortium of 3 institutions: the Oswaldo Cruz Foundation, Núcleo de Estudos e Pesquisas em Atenção ao Uso de Drogas (NEPAD-UERJ), and a facility sponsored by the Catholic

Church, Ambulatório da Providência. This effort cannot be described as a true research protocol but rather as a concerted initiative to provide IDUs with the best practices available concerning medical and psychological care and support.

### **The First Innovative Strategy: Use of a Mobile Unit**

While carrying out the Brazilian Multicenter Study (1994–1996) [33], a former member of our team (W. S. Bastos, Jr.) noticed that patients recruited from drug treatment centers had not benefited from initiatives directed to the prevention of HIV/AIDS or other sexually transmitted or bloodborne infections during the long periods they stayed in the inpatient facilities [34]. Because many of these drug users did not complete their treatment programs and frequently relapsed into drug consumption, they usually returned to engaging in risky injection behavior and/or unprotected sex as soon as they left the clinics [34]. In this sense, our initial strategy of referring HIV-infected patients to appropriate health care after they completed their drug abuse treatment had missed those most in need. Such persons were not exposed to any prevention initiatives other than abstinence-oriented drug abuse treatment.

To address these needs, we assembled a team of 2 physicians from the Ambulatório da Providência, which functioned as a mobile unit that regularly visited the 2 major drug treatment centers of Rio. These visits to the clinics by the mobile task force were very well accepted and stimulated individual counseling sessions, group discussions, and on-site clinical consultations [35]. These activities represented the first attempt to fully integrate outreach activities, referral services, prevention, and treatment and served to foster contact between health care professionals with very different backgrounds.

### **Trying to Integrate Care for IDUs**

The success of the mobile team and the progressive improvement of referring drug users recruited in the community to the Ambulatório da Providência and collaborative projects of Oswaldo Cruz Foundation made this partnership a permanent collaboration, primarily targeting comprehensive prevention and care of people enrolled in different research projects.

The Ambulatório da Providência mainly cares for persons living with HIV/AIDS and/or with other sexually transmitted infections. The vast majority of its clientele belongs to very poor social strata, and many patients are homeless and engaged in marginal and/or illicit activities (e.g., prostitutes, beggars, street children, runaway youth, people smuggling small amounts of illicit drugs). The staff is composed of physicians with backgrounds in internal medicine, infectious diseases, pediatrics, and obstetrics-gynecology; nurses; a psychologist; and a dentist. The outpatient unit is integrated with a hospice where seriously ill HIV-infected adults and children who live in ad-

verse social conditions can be sheltered before and after hospitalization.

The staff at the Ambulatório da Providência provides individualized care of persons living with HIV/AIDS, and also creates initiatives that target larger groups of patients. Cases demanding special management and support are personally overseen by one of us (F.I.B., a psychiatrist by training and a senior researcher in the field of substance abuse) and discussed with the other staff on a regular basis. Each patient is evaluated, at minimum, by a physician, a psychologist, and a social worker. The facility has a 4-bed day care unit, where patients with special clinical, psychological, or social problems can stay the whole day, while taking their medications and undergoing examinations. The Ambulatório da Providência facilities also include showers and an informal food service for all patients enrolled in the day care unit and/or visiting physicians or nurses.

We briefly mention below 3 initiatives that targeted various groups of patients and that were created for the purpose of integrating prevention and care in the Ambulatório da Providência.

**Waiting room debates.** Debates on different topics, coordinated by health professionals from the Ambulatório da Providência, cover a broad range of issues, including aspects related to alcohol and substance misuse and its related harms and how to prevent and manage them. Debates are conducted in the waiting rooms of the Ambulatório da Providência on a regular basis.

**Alcoholics Anonymous (AA) groups.** Three times a week, an AA group meets in a room provided by the Ambulatório da Providência. Although this is an independent activity, as required by AA standards, the group profits from the support provided by the social workers from the Ambulatório da Providência, who try to help the members of the group to fulfill their different needs.

**Antiretroviral therapy adherence group.** A few years ago, the Ambulatório da Providência established a weekly focus group to promote adherence to antiretroviral therapy, an endeavor especially difficult in such a population of dispossessed people, many of them homeless, with a substantial number of persons who abuse alcohol and/or illicit drugs. A large number of patients undergoing antiretroviral therapy have a previous history of alcohol or drug abuse and continue or initiate addiction habits while taking antiretroviral therapy. Therefore, this peer-based adherence group is an important initiative targeting this specific population's needs. As an attempt to improve adherence, role-playing activities involving the management of each of the medicines taken were included in the activities of the adherence group.

Focus group participants were all currently taking HAART and were between 19 and 63 years old. Topics discussed include

daily life; relationships with partners, friends, and family; HAART-related knowledge, attitudes, and experiences; relationships with health providers; and previous and current protective behavior.

Key facilitators of adherence to HAART as identified by participants include communication and relationships with health providers, as well as emotional support and practical assistance provided by the support group itself. Key barriers to adherence include stigma and fear of rejection as a result of disclosing serostatus to partners, relatives, and friends; low self-esteem associated with HIV status and symptoms; the complexity of therapeutic regimens and their side effects; and the concomitant use of alcohol and/or illicit drugs.

According to participants, peer-based support groups function as a “broker” between providers and patients, “translating” technical language into practical information and helping overcome potential power imbalances between doctors and people living with HIV/AIDS. This particular peer-based support group increased the participants’ adherence to HAART, therefore improving their quality of life [36].

Between 1989 and 2002, approximately 16,000 patients were registered at the Ambulatório da Providência. By the end of 2000, a total of 5348 patients had been seen at the Ambulatório da Providência, for a total of 37,838 consultations (each patient had numerous consultations). The vast majority of those patients had a sexually transmitted infection (the focus of the service), although the doors are open for other pathologies.

## LESSONS LEARNED

Brazil is in a unique position among less-developed countries as the only country with a sizeable AIDS epidemic that provides full access to antiretroviral therapy, including related examinations and clinical follow-up, at no cost [3]. Brazil also has a comprehensive range of preventive programs targeting IDUs, including >50 syringe exchange programs, most of them with core funding from the federal government [37].

The Brazilian experience offers many valuable lessons for other countries, even those that are richer and have better staffed health care programs. In some countries, strong resistance still prevails against spending enough funds and engaging a large enough number of health professionals in a comprehensive set of initiatives to curb HIV epidemics among IDUs, their sex partners, and offspring. The cooperative work of professionals, activists, society at large, and networks of international agencies and experts has been pivotal in Brazil to foster HIV/AIDS prevention and care for drug users and to challenge entrenched prejudice and long-time neglect. However, much remains to be done in a huge country where social and economic inequalities and stigma and prejudice against socially

dispossessed communities and minorities still reach unacceptable levels.

To provide antiretrovirals means much more than just delivering them, especially for substance-dependent people, and much has been gained in Brazil in terms of monitoring key factors such as adherence to therapy, development of drug-resistant viruses, and the major side effects of such antiretroviral regimens. These programs must be carefully evaluated to identify their major gaps and to attempt to improve the guidelines and the current operation of each facility and the system as a whole. A specific difficulty still faced by Brazilian IDUs living with HIV/AIDS is the paucity or even absence (in some localities) of services with enough and adequately trained staff to respond to their specific needs. The current integration between services caring for people living with HIV/AIDS and services with expertise in the management of substance use and related harms is poor and should be reinforced between the coordinating bodies at the national, state, and municipal level, but especially at the level of each facility and each community program working with such populations. Brazil still lacks experience in key areas such as the integrated offer of services tailored to the needs of HIV-positive IDUs, despite very recent efforts carried out by institutions in São Paulo and Rio de Janeiro to improve current practices.

The programs implemented in Rio de Janeiro, first with the integrated work of a mobile team in the fields of prevention and care and, especially, with the ongoing experience with HIV-infected IDUs’ case management, should be further explored and thoroughly assessed, to profit from their strengths and to correct their gaps as alternatives to be extended to different settings. After that evaluation, the programs applied in Rio de Janeiro could be attempted or adapted in other contexts, with different drug scene characteristics and fewer resources in terms of funds and trained staff.

There is virtually no expertise in the country in substitution therapies, because, in most settings, cocaine (for which substitution therapies are still experimental) is the sole drug injected, with a negligible role for opiates. Considering the dynamics of drug markets and drug scenes, Brazilian health care professionals should be aware that opioid use might increase in the near future, making substitution therapies a useful resource for the treatment of substance dependence and management of HIV-positive IDUs, as shown by international reports. Syringe exchange programs already implemented in Brazil can function as potential sites for case management for substance-dependent people living with HIV/AIDS.

European countries, such as Spain, have been reporting an increase in the number of people injecting opiates and cocaine, in combination or sequentially, many of whom are already infected with HIV or other sexually transmitted or bloodborne infections [38]. For this reason, Brazil and developed countries

should consider the exchange of experiences in management of HIV-infected IDUs and development of cooperative research projects and therapeutic and preventive protocols a key initiative for both sides.

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